

Proposed Disability Commissioner (Scotland) Bill

Introduction

A proposal for a Bill to establish a Disability Commissioner for Scotland

The consultation runs from 12 May 2022 to 3 August 2022

All those wishing to respond to the consultation are strongly encouraged to enter their responses electronically through this survey. This makes collation of responses much simpler and quicker. However, the option also exists of sending in a separate response (in hard copy or by other electronic means such as e-mail), and details of how to do so are included in the member's consultation document.

Questions marked with an asterisk (*) require an answer.

All responses must include a name and contact details. Names will only be published if you give us permission, and contact details are never published – but we may use them to contact you if there is a query about your response. If you do not include a name and/or contact details, we may have to disregard your response.

Please note that you must complete the survey in order for your response to be accepted. If you don't wish to complete the survey in a single session, you can choose "Save and Continue later" at any point. Whilst you have the option to skip particular questions, you must continue to the end of the survey and press "Submit" to have your response fully recorded.

Please ensure you have read the consultation document before responding to any of the questions that follow. In particular, you should read the information contained in the document about how your response will be handled. The consultation document is available here:

[Consultation Document](#)

[Privacy Notice](#)

I confirm that I have read and understood the Privacy Notice which explains how my personal data will be used.

On the previous page we asked you if you are UNDER 12 YEARS old, and you responded Yes to this question.

If this is the case, we will have to contact your parent or guardian for consent.

If you are under 12 years of age, please put your contact details into the textbox. This can be your email address or phone number. We will then contact you and your parents to receive consent.

Otherwise please confirm that you are or are not under 12 years old.

No Response

About you

Please choose whether you are responding as an individual or on behalf of an organisation.
Note: If you choose "individual" and consent to have the response published, it will appear under your own name. If you choose "on behalf of an organisation" and consent to have the response published, it will be published under the organisation's name.

an individual

Which of the following best describes you? (If you are a professional or academic, but not in a subject relevant to the consultation, please choose "Member of the public".)

Person without a disability.

Optional: You may wish to explain briefly what expertise or experience you have that is relevant to the subject-matter of the consultation.

I'm a carer of someone with Down's syndrome and associated issues, and I've campaigned for the Down's syndrome community for around 10 years.

Please select the category which best describes your organisation

No Response

Please choose one of the following:

I am content for this response to be published and attributed to me or my organisation

Please provide your Full Name or the name of your organisation. (Only give the name of your organisation if you are submitting a response on its behalf).

(Note: the name will not be published if you have asked for the response to be anonymous or "not for publication". Otherwise this is the name that will be published with your response).

Lynn Murray

Please provide details of a way in which we can contact you if there are queries regarding your response. Email is preferred but you can also provide a postal address or phone number.

We will not publish these details.

Aim and approach - Note: All answers to the questions in this section may be published (unless your response is "not for publication").

Q1. Which of the following best expresses your view of the proposed Bill? (Please note that this question is compulsory.)

Fully supportive

Please explain the reasons for your response.

There needs to be better representation for disabled people in Scotland. The pandemic has shone a light and brought that much into sharp focus. We must have better respect for those who are disabled in line with Scottish commitment to disability convention such as the Equality Act and the United Nations Convention on the Rights of People with Disabilities (UN CRPD). During the pandemic disabled people should have been put first, instead they suffered disproportionately. People with Down's syndrome in Scotland were not given treatment for illness, asked to sign up not to come to hospital. Frailty scores were promoted, meaning that those with physical disability would also be refused treatment. The Rockwood scale, an unproven tool originating from Canada is a case in point, and it can still be found online. Alongside that, services for those with disability have still not been fully restored. The price the community has paid in the last 2 years is astronomical.

Q2. Which of the following best expresses your view on whether there is a need for a specific, dedicated commissioner focussing solely on people with a disability?

Fully supportive

Please give the reasons for your response

We would consider ourselves as a civilised and caring country and we have structures in place to indicate that to be the case. But the arrival of Covid challenged our civility, as soon as we feared the consequences of Covid, the very structures set up to help the vulnerable used tools at their disposal to free up medical resources for the previously healthy. Society became disordered. This is deeply troubling and there needs to be direct responsibility and accountability shown by the Parliament going forward. We must ensure that the lived-in experience is considered at all times, not merely in the time of our choosing, People with disabilities need an advocate inside the Parliament who is co-working with disabled groups and those with the lived-in experience.

Q3. Do you think legislation is required, or are there other ways in which the proposed Bill's aims could be achieved more effectively? Please explain the reasons for your response.

We have a strong commitment to human rights legislation and convention, sadly, it appears that we as a nation are failing to meet the standards to which we've subscribed to. The Government has introduced the concept of a learning disability bill but this will not bear any fruit for some time and it's unclear as to how much it will help the disabled who need resources to be able to live an equal life whilst there's a focus on neurodiversity, which may not be about those who are disabled, and this may water down the positive effects for the disabled, as opposed to the necessary re-doubling of efforts. Any bill needs to include those with physical and learning disabled. There needs to be better commitment to caring for the most vulnerable people in our society, and law which incorporates the principles of the UN CRPD could do that.

Scope of the Disability Commissioner Role

Q4. Which of the following best expresses your view of the Disability Commissioner role covering all disabilities; physical, mental, hidden and fluctuating conditions?

Fully supportive

Q4. Which of the following best expresses your view of the Disability Commissioner role covering all disabilities; physical, mental, hidden and fluctuating conditions?

Please give reasons for your response, including how the commissioner could co-ordinate with the work of existing bodies/organisations who support people with these conditions.

The social model of disability and the UN CRPD need to be the focus for a disability commissioner and this doesn't distinguish between disabilities. There has to be recognition that during the last 2 years that both those with physical disabilities and learning disabilities and other conditions became 'second-class' citizens. Necessary services were withdrawn and the consequences of this phenomenon have not yet played out. The social model of disability was in effect discarded, and we need to restore that as a standard to which we adhere. A commissioner would be expected to support the continuation of the current work being done, but a strength could be that they would represent a larger group of people who tend to suffer the same discrimination and issues and this could provide a stronger voice for the disabled community.

Q5. Which of the following best expresses your view of the Disability Commissioner having a role in reviewing laws and policies that might impact on disabled people?

Fully supportive

Please explain the reasons for your response.

We need to have more consideration on the impacts of laws and policies on those with disability. In my experience as an NHS external stakeholder, there seems to be a complete lack of knowledge and education on what it's like to live with disability, there's a tendency within authorities to focus on the medical model. There is also no real understanding that an impact assessment should be meaningful and lead to change and revision of policy particularly when a policy impacts on a disabled group. To give an example: My suggestion that there could be a reference in pregnancy screening literature to a group entitled 'positive about Down syndrome' was met with a look of horror and a response that if that was to be included then there would have to be a reference to a group with the opposite view. This to me showed a complete misunderstanding of disability equality, human rights for the disabled, and I realise there was no malice intended, this is merely a medical perspective and not one that should be proliferated.

Q6. Which of the following best expresses your view of the Disability Commissioner promoting best practice and learning from service providers, key stakeholders and third sector?

Partially supportive

Please explain the reasons for your response, including how you envisage this work being undertaken?

The disability commissioner needs to be coming from and promoting the human rights of those with disability plus the UN convention on the rights of people with disabilities. Alongside that, the stakeholders are important in helping to advise, promote and illustrate best practise where they're exercising that or where they see it.

Q7. Which of the following best expresses your view of encouraging involvement of disabled people and DPOs (Disabled People's Organisations) in the work of the Disability Commissioner?

Fully supportive

Please explain the reasons for your response. Please discuss how you think this would work in practise – would this be through focus groups, internships, paid roles etc

The disability commissioner must be employing people with disabilities and co-working with disabled people and their organisations. They must also be promoting the employment of those with disabilities

Q7. Which of the following best expresses your view of encouraging involvement of disabled people and DPOs (Disabled People's Organisations) in the work of the Disability Commissioner?

within Government bodies. But in order for that to happen on an ongoing organic basis, the commissioner needs to ensure more inclusion in education for those with disabilities.

Q8. Who should the Disability Commissioner be allowed to investigate?

No Response

Financial Implications

Q9. Any new law can have a financial impact which would affect individuals, businesses, the public sector, or others. What financial impact do you think this proposal could have if it became law?

no overall change in costs

Please explain the reasons for your answer, including who you would expect to feel the financial impact of the proposal, and if there are any ways you think the proposal could be delivered more cost-effectively.

It's difficult for me to calculate the effects of a more inclusive society, and my answer is a neutral one at this point. The inclusion of more people in mainstream education would lead to a reduction in financial costs and intangible social benefits. Initially, there may be extra cost, but I believe that this will be paid back as the fruits of inclusion are reaped. Earlier medical intervention could reduce medical costs over a person's life and if we were to tackle the problem of medical overshadowing then we would reap the benefits of this too.

Equalities

Q10. Any new law can have an impact on different individuals in society, for example as a result of their age, disability, gender re-assignment, marriage and civil partnership status, pregnancy and maternity, race, religion or belief, sex or sexual orientation.

What impact could this proposal have on particular people if it became law? If you do not have a view skip to next question.

Please explain the reasons for your answer and if there are any ways you think the proposal could avoid negative impacts on particular people.

People with Down's syndrome experience more and longer hospital stays as children than others and we must understand why this is happening and how we can change that situation for the better. People with Down's syndrome die 28 years earlier than others in the population. These two stark facts mean that there is plenty of scope for positive impact on that community. People with Down's syndrome are to be mainly attending special schools when we know that they can benefit from inclusion in the mainstream sector. Even in further education in Scotland, people with Down's syndrome are streamed into segregated courses, this is a practise that could end if there were policy/legislative change introduced. A school census of the group could provide helpful data to advise practise.

References: <https://bmjopen.bmj.com/content/10/4/e033770>

<http://www.sldo.ac.uk/our-research/life-expectancy-and-mortality/life-expectancy-and-causes-of-death-of-people-with-down-syndrome/>

<https://library.down-syndrome.org/en-gb/research-practice/09/3/comparison-mainstream-special-education-teenagers->

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down-syndrome-implications-parents-teachers#:~:text=That%20all%20children%20with%20Down,numeracy%20skills%2C%20and%20general%20knowledge.

Sustainability

Q11. Any new law can impact on work to protect and enhance the environment, achieve a sustainable economy, and create a strong, healthy, and just society for future generations.

Do you think the proposal could impact in any of these areas? (If you do not have a view then skip to next question)

Please explain the reasons for your answer, including what you think the impact of the proposal could be, and if there are any ways you think the proposal could avoid negative impacts?

I've no real knowledge in this field, but I do know that we have to stop thinking in terms of centralisation of services leading to increase in travel for many in this group as a benefit to the environment (without consideration of the other equally important benefits.)

General

Q12. Do you have any other additional comments or suggestions on the proposed Bill (which have not already been covered in any of your responses to earlier questions)?

Scottish Government must inform itself of the very real impacts that the last two years have had on the disabled community, they must gather and consider the anecdotes of the actual experiences that people with disabilities have undergone, without consideration of the lived experience, the matter remains academic, and that isn't acceptable if we want to consider ourselves a progressive society.